Social work should be more proactive in addressing the need to plan for end-of-life

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Abstract

Few people engage in planning for life's end and the prevalence of preparedness is particularly low in ethnic communities. As a profession, social work is well equipped to help increase planning for life's end and the care people wish to receive. However, the profession cannot simply defer to those in hospice and palliative care settings to address this issue. There is a need for earlier and equitable access to death preparation, and social workers can be instrumental in helping to insure equal opportunities for proactive planning for death. The ways social work may become more proactive in assisting individuals and families to prepare for the end-of-life are discussed.

Key Words: End-of-life, death, dying, advance directives

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Death is a certainty of life but one that receives little planning. Proactive planning involves advance decisions for end-of-life (EOL) care, the transfer of goods or wealth, and such practical considerations as the disposition of human remains and funeral or memorial service preferences (Bern-Klug, Ekerdt, & Wilkinson, 1999). These often call for interactions within legal, familial, and healthcare systems (Kelly, Masters, & DeViney, 2013).

We assert that the profession of social work is well positioned to extend opportunities for people to plan proactively for their own death. Social workers in palliative and EOL care are responsive to the need for death preparation as evidenced by the development of professional competencies and standards of practice (Gwyther et al., 2005; Kramer, 2013). Yet there remains a need for wider attention to earlier planning for death.

One estimate suggests that 27% of adults have given little to no thought to their EOL care, and while 35% have given some thought to the issue, the majority have neither documented nor discussed their preferences with others (Pew Research Center, 2013). Developing a care plan assists people to obtain the desired type of care as they near death (Detering, Hancock, Reade, & Silvester, 2010) and reduces stress for surviving family members (Bern-Klug et al., 1999).

While time horizon and illness certainly play a role in determining whether planning occurs (Moorman & Inoue, 2013), evidence also points to the importance of social factors. In the U.S. people who are from minority racial and ethnic groups are less likely to have engaged in death preparation (Gerst & Burr, 2008; Kelley, Wenger, & Sarkisian, 2010). Moreover people with greater socioeconomic status have a higher rate of participation in activities such as writing wills and advance care planning than those with lower socioeconomic status (Kelly et al., 2013). These findings suggest that those with the tangible resources to navigate the systems involved with proactive planning benefit from preparation.

People who are suffering from terminal illnesses are often incapable of making decisions about their medical treatments or directing their EOL care. Research with a nationally representative sample of older Americans found that approximately 30% of decedents needed treatment decisions but were unable to make such decisions on their own (Silveira, Kim, & Langa, 2010). When the dying person cannot express what he wants for his medical treatment, he needs a surrogate decision maker, usually a family member and typically the spouse if the person is married (Carr & Khodyakov, 2007). Therefore, it is important to have EOL treatment preferences known to people who might have to make decisions. Having a formal EOL care plan helps this process (Inoue & Moorman, 2014).

People may think that proactive planning for death is needed only when they become older; however, death can happen at any age. Moreover, because the completion of EOL planning involves a series of steps, including contemplation, discussion, and documentation (Sudore et al., 2008), early preparation is important not only for older people but also for younger and healthier people.

In the absence of advance care planning and clear communication with others, life-sustaining interventions are normative even as they may add to the discomfort and distress of patients and their family members and may be inconsistent with patients' wishes (Detering et al., 2010; Inoue & Moorman, 2014). Aggressive treatment occurs more often for minority patients, who are less likely to use hospice and are at greater risk for spending their last days in hospital (Hanchate, Kronman, Young-Xu, Ash, & Emanuel, 2009).

A compression of healthcare usage occurs in proximity to death, which is associated with greater healthcare costs (Kelley et al., 2011). If death preparation remains low, expenditures are likely to rise substantially given the size and diversity of the older adult population (Harper,

2014). Whether the costs associated with medical diagnostics and treatment at the EOL is sustainable over upcoming decades remains questionable. More needs to be done to increase death preparedness and in turn reduce unwanted medical procedures while providing desired care for all.

The person-in-environment perspective and professional values that guide social work practice provide a foundation to supporting individuals and families as they proactively plan for death. The NASW (2008) ethical commitment to clients' self-determination and recognition of the worth of each person, the importance of relationships, service, and integrity are crucial elements in addressing this sensitive topic. Under these principles social workers are trained to function in multiple roles in micro practice such as educator and broker (Kramer, 2013). Without such person-centered approaches individual preferences for care may be misidentified or misinterpreted as evidenced by the incongruity between expressed preferences for non-institutionalized death and the actual death experience of millions (Inoue & Moorman, 2014).

Further, social workers are well versed in working with family systems as they navigate complex healthcare and decision-making processes (Dubus, 2010). Social workers are innovative and willing to form partnerships with other community leaders and professionals, and these interventions may lead to new community services to address the last stage of life (e.g., Kintzle & Bride, 2010).

In addition to individual preferences, culture influences EOL care decisions (Bullock, 2011; Kelly et al., 2013). African-Americans may place trust in faith and familial systems instead of legal and medical systems (Bullock, 2011; Gerst & Burr, 2008). Further, Latinos may prefer family decision-making over autonomous choices regarding EOL decisions, although acculturation and health literacy need to be considered (Kelley et al., 2010). Lack of information

about the need for planning and hospice care is a known barrier to usage in ethnic communities (Jang, Chiriboga, Allen, Kwak, & Haley, 2010). Social workers often occupy positions that engage ethnic communities and can be instrumental in reducing these barriers.

As the profession is increasing competencies in the delivery of culturally relevant care and assuming coordinating roles within healthcare systems, the discrepancy between desired EOL preferences and delivery of palliative care can be reduced by expanding the conversation and preparation for death. On a micro level social workers can help individuals and families negotiate the planning process, at the community level social workers can conduct culturally appropriate outreach, and at the organizational level social workers can help develop innovative EOL planning or care models. The profession of social work with its commitment to compassionate social justice must insure equitable access to early death preparation and EOL care.

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